



## The University of Utah

Utah Registry of Autism  
and Developmental Disabilities

May 10, 2011

Jocelyn Taylor, Education Specialist  
Utah State Office of Education  
250 East 500 South  
P.O. Box 144200  
Salt Lake City, UT 84114-4200

Re: Prevalence of Autism Spectrum Disorders (ASDs) in Utah

Dear Jocelyn,

Thank you for the opportunity for the Utah Registry of Autism and Developmental Disabilities to contract with the Utah State Office of Education in collaboration with the Utah Department of Health to measure changes in autism prevalence in Utah. By way of background, the registry measures ASD prevalence by two methods: 1) use of multiple administrative dataset's diagnostic coding and school special education classifications and; 2) the Centers for Disease Control and Prevention's (CDC) Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) methodology that includes an expert clinician review process.

Utah's 2008 administrative prevalence data (an ASD health diagnosis and/or autism special education classification) published in the Journal of Autism and Developmental Disabilities last week derived from multiple school and health sources showed that ASD prevalence in Utah children aged eight doubled over the last six years (2002-2008). The administrative prevalence rose from 1 in 154 in 2002 to 1 in 77 in 2008 (Pinborough-Zimmerman et al, 2011 ).

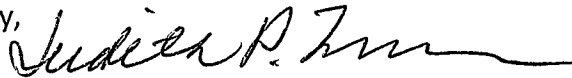
You asked for written clarification on the contribution increases in the number of children with school autism classification plays in overall increases in autism prevalence in Utah. First, health sources diagnose ASD almost twice as frequently as schools assign an autism classification. Second, the growth in the number of children with autism exceptionalities is paralleling the growth in ASD health diagnoses but a large gap remains. Third, of children with an ASD diagnosis the majority were not receiving special education services under an autism classification. In other words, only 1/3 of children with an ASD health diagnosis had a school autism classification. Fourth, without school data, the overall ASD administrative prevalence in 2002 would only have been reduced only by 12% and by 17% in 2008. Lastly, with or without the contribution of school data, the rates of ASD's in Utah still would have doubled from 2002

to 2008. We do feel however, that collaboration with the schools is essential in understanding the scope and impact ASD has on our community.

Of importance is that Utah's 2008 administrative rate is significantly higher than nine of the ten sites who reported prevalence findings in the December 2009 Morbidity and Mortality Weekly Report for study year 2006. We are now in the process of finalizing our 2008 ASD prevalence rate including race/ethnicity using the MADDSP method along with thirteen other U.S. sites under the direction of the CDC. When that data becomes available, with approval from the CDC, I would be happy to review the findings with you. In the interim, of interest to you may be a national report from the CDC published in the December 2009 Morbidity and Mortality Report that that found ASD prevalence estimates for Hispanics was significantly lower than for non-Hispanic children across the US.

We realize that the growth in the number of children with ASD health diagnoses is placing an extreme burden on service delivery providers, particularly public school special education programs. We strongly believe that autism is an urgent and growing public health and education concern and look forward to our continued collaboration.

Sincerely,

A handwritten signature in black ink, appearing to read "Judith P. Zimmerman", with a long horizontal flourish extending to the right.

Judith P. Zimmerman, Ph.D.

Assistant Research Professor, Director of URADD

University of Utah